



BUILDING A MEDICAL HOME FOR CHILDREN WITH ASD AND THEIR FAMILIES

In collaboration with the Washington Autism Advisory Council

BUILDING A MEDICAL HOME FOR CHILDREN WITH ASD AND THEIR FAMILIES

- ◎ **WHAT?** A one day CME conference and corresponding online training modules (tentatively Complementary/Alternative Medicine, Transition, Advocacy/Appeals).
- ◎ **FOR WHOM?** Primary care providers, including pediatricians, family medicine, ARNPs in Washington State.
- ◎ **WHEN?** Saturday, October 10, 2015
- ◎ **WHERE?** Seattle Childrens Hospital, ? a second offering in Eastern WA.
- ◎ **WHY?** See next slide.



WHAT IS A MEDICAL HOME?

- ◎ A "Medical Home" is a process of primary care that *provides accessible, family centered, coordinated, compassionate, comprehensive, continuous, culturally sensitive care.*
- ◎ Children with ASD:
 - Have greater health care utilization than other children. 98% seek specialty services (children under 11, majority use ≥ 3 services).
 - Are less likely to have a medical home (23.9%) compared to other CSHCN (43%) or all kids (57.5%).
 - Are more likely to have unmet needs (63%).



NS-CSHCN 2009-10
Lin, Rev J Autism Disord 2014

CHILDREN WITH ASD

- ◎ Have more medical visits
- ◎ Have more medical co-morbidities
- ◎ Have ≥ 3 times more medical care costs than children without autism



Myers, 2007; Croen, 2005

HOW DOES A STRONG MEDICAL HOME IMPROVE HEALTH CARE FOR CHILDREN WITH ASD?

- ◎ Aligns family needs with provider
- ◎ Provides care coordination and communication with the Medical Neighborhood (non medical providers, schools, state/local resources, insurance, respite).
- ◎ Children with ASD who have "medical home":
 - > 4X more likely having needs met¹
 - Improved health outcomes²
 - Lower financial family impact²
 - Lower family stress²

¹Cheek-Zamora, 2014
²Kogan, 2006



PRIMARY CARE PROVIDERS PLAY A CRITICAL ROLE IN THE CARE OF CHILDREN WITH ASD

- ◎ On average, PCP care for ~10 children with ASD^{Desires, 2}
- ◎ PCPs identify barriers:
 - Lack of coordination.
 - Lack of time . .
 - Lack of reimbursement . .
 - Lack of provider education, practice guidelines .
 - Family skepticism .
 - Lack of awareness of community resources .
 - Lack of expertise in behavioral management .

Golink, 2009¹
Carbone, 2010²
Carbone 2013³

PCPs SAY THEY NEED:

- More training in how to provide primary care to children with ASD ,
- More training in ASD co-morbidities ,
- More information about Complementary and Alternative Medicine, about vaccine refusal ,
- A compilation of community resources, including family groups and school programs ,
- Evidence-based guidelines for children with ASD ,
- Insurance reimbursed care coordination ,
- More information about transition planning ,

1 Golnik, 2012, 2 Carbone, 2010

PREDICTORS OF (SELF PERCEIVED) PROVIDER COMPETENCY

- ⊙ For primary care Medical Home:
 - Greater number of patients with ASD
 - Receiving ASD education in residency
 - Having a friend or relative with ASD
 - Receiving ongoing Continuing Medical Education on ASD
- ⊙ For recommending ABA treatment:
 - Greater number of patient with ASD
 - Having a friend or relative with ASD
 - Receiving ongoing Continuing Medical Education on ASD

FAMILY PERSPECTIVE

- ⊙ PCPs busy, provide well child & illness care ^{1,2}
- ⊙ PCPs not knowledgeable about ASD ^{1,3}
- ⊙ Services across multiple sectors ^{2,4,5}
- ⊙ Difficulty accessing specialty services ^{1,4}
- ⊙ Parents main care coordinators ,
- ⊙ Parents do not feel valued as experts on child ,
- ⊙ High financial and emotional stress ^{1,4}

1 Carbone 2010 2 Farmer 2014 3 Hargunani 2006 4 Cheek-Zamora 2014 5 Golnik 2012
6 Autism Speaks 2009

FAMILY UNMET NEEDS

- ⊙ PCPs more responsive & reactive to parental concerns about behavior and development ,
- ⊙ Adequate counseling for Dx and Tx options ^{1,2}
- ⊙ Shared decision-making for CAM & vaccines ^{3,4,5}
- ⊙ Community resources information ,
- ⊙ Care coordination ,
- ⊙ Family needs change as child grows ⁶
 - Early diagnosis
 - Mental/behavioral health
 - Transition to adulthood

1 Zuckerman 2014 2 Major 2013 3 Carbone 2013 4 Golnik 2012 5 Carbone 2010
6 Volkmar 2014



WAAC DISCUSSION

?MOST IMPORTANT TOPICS?

	PARENT	PROVIDER
MEDICAL HOME	<ul style="list-style-type: none"> •Logistics in office •Medical necessity for services •Shared decision making •Transition, puberty, QOL •Caregiver stress 	<ul style="list-style-type: none"> •Logistics in office •Co-morbidities (seizures, procedures, sleep, GI, behavioral and mental health problems, CAM, vaccines •Reimbursement
MEDICAL NEIGHBORHOOD	<ul style="list-style-type: none"> •Access to services •Need care coordination •Communication with other providers, school •Caregiver stress 	<ul style="list-style-type: none"> •Access to specialists •Knowledge of local resources •Knowledge about ABA and other evidence-based interventions

AN "OPPORTUNITY" FOR WAAC?

⊗ Should we consider providing PCPs and their office staff with a :

- "STATE OF THE STATE"-to review before the conf?
- AN UPDATED GUIDEBOOK?
- An online RESOURCES BY ZIP CODE
- CREATE AN ONLINE MODULE?
- MEDICAL NEIGHBORHOOD ?
- OTHER IDEAS?

DEADLINE: OCTOBER 10, 2015

CONTACT US!

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